

**Children's Special Health Services  
Family Advisory Council Meeting**

**Saturday, March 5, 2011 – 9:00 a.m. to 12:00 p.m. CST  
Comfort Suites – Bismarck, ND**

**Welcome/Introductions/Announcements**

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Laura Roberts, Lisa Beckman, Evelyn Klimpel, Donene Feist, Cheryl Klee, Lori Hanson (phone), Moe Schroeder, Jennifer Restemayer, and Twyla Bohl.

Present from Children's Special Health Services Division: Sue Burns, Kim Hruby, Melissa Evans, Devaiah Muccatira, Alicia Phillips, and Tammy Gallup-Millner.

Tammy and other Family Advisory Council members provided the following updates or announcements:

- Moe Schroeder was welcomed as a newly appointed CSHS family advisory council member.
- Donene Feist received the Champion in the Field of MCH award and was an AMCHP Conference Plenary speaker. Note: Donene's speech titled *Barriers to Health Care Reform* has been enclosed along with the meeting minutes.
- Lori Hanson and Cheryl Klee participated in the Early Childhood Legislative messaging project. Their photos and stories were shared with group. Lori relayed that Vocational Rehabilitation will be paying for a stethoscope to accommodate Alicia's hearing loss. Cheryl said that she received a response from a legislator regarding her story.
- The newspaper story on Laura's wrestler son Cole Roberts was shared with the group. Laura also relayed that Verizon accommodated Cole, who is blind, with a phone that reads everything back to him.
- Lisa Beckman has a new granddaughter named Madison Jane who was born on January 24, 2011.
- Jennifer Restemayer's daughter Allison created "Team Ali Rocks" for the Make a Wish walk in conjunction with her 10<sup>th</sup> birthday.
- Twyla Bohl shared that she has a new grandson and that Matthew is now driving with hand controls and has a job.
- Evelyn Klimpel shared that her son finished his first semester in college and is doing well. Evelyn also relayed that she is involved with an e-text (electronic textbook) project for Tribal colleges and has organized the campus Pow-Wow.
- Tammy reminded the group about the Family Voices Parent Leadership Institute, which is scheduled for June 3-5, 2011 in Edgeley, ND.
- Tammy routed the Family Advisory Council membership list to make sure information was up-to-date.

**Follow-up from November 2010 Meeting**

The November 20, 2010 Family Advisory Council meeting minutes were accepted as written.

Items on the Review/Recommendation Summary form for the November 20, 2010 meeting were reviewed with council members. The membership list was updated and disseminated. Moe Schroeder was recruited and subsequently appointed to the council by the State Health Officer in February 2011. An update on home visiting was included on the agenda as part of the discussion with the Health Department's budget. The MCH 75<sup>th</sup> slide show and Life Course game will need to be addressed at a future meeting. CSHS staff followed up with Cheryl Klee and Lori Hanson who submitted photo's and letters about their family experiences for the early childhood Legislative Messaging Project.

## **Updates**

### National Update

Tammy shared a health care reform handout from the Catalyst Center titled "The Affordable Care Act" which highlights major provisions of the law along with the implications for children and youth with special health care needs.

Tammy relayed that a Continuing Resolution is in effect that provides federal funding through March 18, 2011. A budget cut of \$210 million, which equates to about 30%, could be a possibility at the federal level for the Title V MCH Block Grant. More recently, a \$50 million cut was proposed. In response to this threat, the Association of Maternal and Child Health Programs is planning to provide information on activities supported through the Title V Block Grant at the federal level. Within the Department of Health, information had been compiled about possible consequences such a cut would have for the MCH population in ND. Donene recommended families from the advisory council contact ND's Congressional delegation to share their family stories.

Tammy asked for suggestions on what to cut if funding were reduced by 25%. Some ideas included across-the-board cuts for all CSHS programs, eliminating potentially duplicative clinics (myelodysplasia or autism), reductions to information and referral services, and elimination of stipends to Family Advisory Council members.

### Department of Health Update

Tammy shared highlights from the ND Department of Health's testimony on House Bill 1004, the department's budget bill. Dr. Dwelle, the State Health Officer provided an overview of the department and the status of health in ND. Arvy Smith, the Deputy State Health Officer provided a budget overview. The state general fund provides only 15 percent of the department's funding. Two significant budget challenges for the Health Department follow:

- Federal Funding Issues – The future of many federal funding sources is uncertain.
- Community Health Trust Fund – The Department of Health's share of the tobacco settlement dollars is no longer adequate to support program spending.

House amendments to the Department's budget bill affected the following: the regional public health network, salary equity, prenatal alcohol screening, emergency medical services, an injury prevention/domestic violence grants manager, Protect ND Kids, and health reform. The latter included funding for intensive home visiting to high risk families. The state applied for funding which would support evidenced-based programs which are proven to reduce child abuse and neglect and increase education outcomes.

Tammy also relayed that Emergency Preparedness training is underway for possible flooding and other natural disasters. Alicia gave a brief overview from the training she had recently attended. The Family Voices website has information on disaster preparedness for children with special health care needs for those who are interested in proactively planning within their family and in their community.

#### Department of Human Services Update

Sue provided a legislative update regarding eligibility for the Children's Health Insurance Program (CHIP). HB 1377, SB 2135, and SB 2264 all failed, but funding within the DHS budget bill was included for CHIP at 175 percent of poverty. This will be monitored for changes once it goes to the house. Kim shared information on SB 2298, a bill that addresses childcare for children with special health needs and SB 2268, a bill addressing autism.

#### **CSHS Division Program overview and Activity Update**

##### Administration

Tammy relayed that the service contract application packets for the upcoming biennium will be mailed out in the next couple weeks. These contracts provide funding for multidisciplinary clinics, community-based care coordination, family support services, and medical home infrastructure.

Tammy provided updates on a few of the committees that have CSHS staff representation including the following:

- Autism – CSHS continues to monitor implementation of the state plan and any successful legislation.
- SHEW – CSHS is monitoring legislation that addresses coordinated school health and attending scheduled meetings.
- SCDD – A strategic plan is under development. CSHS has successfully advocated that health be included as a priority area within the new five-year plan.

##### Specialty Care Diagnosis and Treatment Program

Melissa relayed she is coaching county social workers regarding options to better help families (e.g., ways to reduce cost share). With claims payment, unique coding issues within CSHS are being addressed (e.g., need for new clinic-related codes). Melissa also shared that Medicaid implemented a new system called 'Blood Hound' this past fall, which should be beneficial to CSHS.

##### Multidisciplinary Clinics

Staff relayed that the new 2011 clinic directory is out and has been updated on the CSHS web page. The pediatric specialist pages are a much appreciated addition to the directory. Staff also shared a concern that providers are sometimes not able to stay for the full duration of a clinic. In such instances, families have expressed frustration in not being able to see the full team.

##### Metabolic Food Program

Tammy relayed that efforts to expand the metabolic food program have been curtailed as SB 2212 and SB 2153 both failed. The only bill left is SB 2067 which includes housekeeping language expanding metabolic screening to "metabolic and genetic screening". Donene requested that expansion of the metabolic food program be considered for OTC and other

disorders. Jennifer asked whether CSHS could pay a certain amount for formula and then have the family pay the difference if they need something that is currently not provided through the DoH. This could be explored but Tammy did not think current state law addressed that option.

Tammy also shared a mailing issue the division encountered when some formula was exposed to extreme weather conditions. To address the issue, a signature is being required upon delivery to reduce potential formula loss. Tammy stated that direct shipping to the family may be a future solution. Currently, formula is stored in CSHS and mailed to families upon their request.

#### Russell Silver Syndrome Program

Melissa provided an administrative story related to family travel reimbursement. A family served by CSHS received a 1099 through the MMIS because reimbursement for travel was over \$600. The family informed CSHS this was an error because travel reimbursement shouldn't be counted as income. After researching the issue, CSHS staff agreed and resolved the issue in a timely manner within the DoH and DHS. Delays in travel reimbursement the previous year were also discussed. CSHS requires medical reports be provided to verify that an out-of-state consultative visit occurred. The group indicated CSHS was using due diligence and recommended a letter be sent to the family prior to their out-of-state visit explaining the requirements for travel reimbursement and the need for a medical report before any payment is made by CSHS. A meeting with the family to discuss issues in person could also be considered.

#### Care Coordination

Kim relayed that an assigned social worker handles CSHS casework in each county and completes the care coordination plans. The one area that is consistently weak is medical needs and management. Since medical reports are required, local staff include limited information in this section of the plan even though information regarding both the child and family is helpful. Cheryl stated that social workers are not asking the right questions therefore it is hard for families to understand. Twyla relayed that she was asked to fill out as much as she could on her own and then come in to fill out the parts she didn't understand. Recommendations from council members included the following:

- Have Family Voices assist in training the social workers.
- Have Family Voices staff fill out the form if an authorization is completed.
- Hire someone to complete the medical assessment portion of the care coordination plans.

Kim shared a positive story regarding a specific county worker who received a "Thank You" from a family.

#### State Systems Development Initiative

Devaiah plans to create topical fact sheets for the MCH population and asked for input from the group on which topics would be most useful in our state. If time permits, input from family advisory council members will be solicited regarding their ideas on the most important topic areas. Donene recommended that the fact sheets be shared with the family advisory council.

#### Other Agenda Items

Family Advisory members recommended information be sent out on agenda topics that could not be covered due to meeting time constraints (e.g., public information services – resource booklets

and Facebook update, CSHCN systems development report, etc.). Note: Additional information has been enclosed along with the meeting minutes.

**Designee for attendance at May Medical Advisory Council meeting**

Lori Hanson volunteered to be the designee at the upcoming Medical Advisory Council meeting. Moe Schroeder will also participate.

**Reimbursement Forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**Next Meeting**

The next Family Advisory Council meeting is scheduled May 7, 2011 from 1:00 to 4:00 p.m. This is a change from the council's usual meeting time due to the annual Medical Advisory Council Meeting.